

Internet Research On-line Surveys

Basic Premises

- While internet research presents some new challenges for the IRB, particularly around privacy and confidentiality, it poses no more risks, in and of itself, than other forms of behavioral and epidemiologic research.
- Many of the issues and concerns raised about Internet research also exist in mailed and telephone survey research.
- The existing ethical and regulatory framework used by IRBs is quite adequate for reviewing Internet research.

Internet Research – Three Aspects

- Recruiting Subjects over the Internet
- Observation of Internet Activity (e.g., chat rooms or on-line forums)
- On-line surveys

On-line Surveys

Advantages (Methodological)

- Access to large numbers of potential subjects.
- Low cost, and in particular, a low marginal cost of additional subjects.
- Flexible - compared to mail surveys, but similar to CATI telephone surveys, you can pose different questions to people depending on their response to previous questions.
- Less error-prone – data are compiled automatically – no need for human keying or transcription of data.
- Real-time compilation of study data.

Disadvantages (Methodological)

- Questionable external validity – To what group can you generalize the findings?
 - Unlike RDD surveys, there is no sample frame that provides a random sample of Internet users.
 - Especially problematic to generalize from an Internet sample to the general pop - Internet users are more likely to be White and young.
 - Also, bias introduced by self selection and low response rates.
 - These problems are mitigated when the Internet is used only as a vehicle for administering a survey to a previously selected sample of individuals.

Disadvantages (continued)

- Lack of control over the research environment.
 - Difficult to verify who participates, and whether subjects are honestly stating their age – e.g., when surveys are intended for adults, difficult to determine whether minors are inappropriately participating.
 - Difficult to determine if people are participating frivolously or maliciously in a way that could undermine the integrity of the study, e.g., multiple submissions by the same individual may bias results
 - On-line surveys may require larger samples than phone or mailed surveys to compensate for greater error related to these factors.
 - Again, these problems are mitigated when a previously identified sample of individuals is invited to participate in an on-line survey; e.g., passwords for accessing a site can be issued and IP addresses can be tracked.

Protection of Human Subjects - Risks

- Not all of these issues are unique to on-line surveys; many also exist in mailed and phone surveys.

Risks - Adverse Psychological or Emotional Reactions

- Individual adverse reactions to sensitive or personal questions or issues posed in the survey, including those that may evoke painful memories from subject's past experiences (e.g., surveys exploring history of domestic or child sexual abuse).
- Not unique to on-line surveys, but more difficult to plan for or deal with than in-person or telephone surveys, although mail surveys are equally problematic.
 - Usually addressed by having resources available for subjects who are experiencing emotional reactions – this can be done in on-line surveys, but the impersonal nature of the survey precludes real-time personal interaction with the researchers.
 - Mitigated by ease of withdrawal from the on-line survey environment.
- This is less of an issue with minimal risk surveys with few if any personal or sensitive questions or issues.

Risks – Related to Deception

- Some study designs require not fully informing subjects of the purpose of the research in advance of the data collection, because to do so would bias their responses.
- Requires the IRB to approve a waiver of some elements of consent.
- Requires that subjects be debriefed at the end of the study (i.e., end of data collection) to explain why some information was withheld, and to assess whether a subject is upset.
- While debriefing information can be provided at the end of an on-line survey, or even made available to subjects who leave the site before completing the survey, it's not possible to assess the subject's state, determine if he/she is upset about the deception, or even if he/she understands the debriefing information.

Risks – Breach of Confidentiality

- The greatest risk in on-line surveys is the possibility that identifiable private information will be disclosed outside the research setting.
- Risks of accidental disclosures occur at each of three points in the data collection process: 1) Communication between the researchers and the subject; 2) Communication between the subjects and the web server; and 3) Communication between the web server and the researcher.
- Risks can be mitigated by ensuring the security of the data transmission process (e.g., password protection, encryption, and use of Secure Socket Layer (SSL) protocols and Secure File Transfer (SFT) protocols).
- Risks can also be mitigated by using standard procedures required for management of all datasets containing identifiable private information (e.g., removal and segregation of all identifiers from survey data)
- Whenever possible, conduct the survey anonymously, but that's not as straightforward as it might seem.
 - For example, IP addresses are typically obtained when the subject interacts with a web server. If using a personal computer, the IP address essentially identifies the subject. (Note: Under HIPAA, IP Address is an identifier)
 - There are ways to address this problem, such as dynamic IP addressing systems, or anonymizing the data as it's pulled from the website and stored in a database.
 - Claims that survey participation is anonymous should not be accepted unless the researcher specifically explains how anonymity is achieved.

Protection of Human Subjects - Informed Consent

- As with risks, many of the issues involving informed consent are not unique to on-line surveys.

Informed Consent – Presenting the Information

- Unless waived by the IRB, all the required elements of consent must be presented before the subject enters the survey page.
- The subject should have some means of indicating consent to participate – usually by a “click to accept” statement.
- This is no different than any other survey or interview research.

Informed Consent – Comprehension

- In on-line surveys, determining comprehension presents challenges and opportunities.
- Compared to in-person or telephone interviews, this may be more difficult; there is no opportunity to interact with the subject.
- Compared to mailed surveys, there are some options; for example:
 - Requiring a “click to accept” for each element of consent, or
 - Administering a short quiz about the study before subjects move to the survey pages.
- Ensuring comprehension is more important as the risks to subjects increase.

Informed Consent – Withdrawal from the Survey

- As in any survey or interview, subjects have a right to quit at any time. While this is ostensibly easy to do in an on-line survey, issues related to the retention of data already submitted should be addressed in the consent.
- Also an issue is whether the survey is designed so that questions can be skipped by the subject; if not, this should be explained in the consent.

Informed Consent – Participation of Minors

- Minors cannot legally consent to participate in research; thus, unless the requirement is waived by the IRB, parental permission for the participation of a minor is required for on-line surveys, just as it is in mailed, telephone and in-person surveys.
- This requirement is compounded by the difficulty of distinguishing between adults and minors in on-line surveys (unless the sample is selected beforehand).
- One way of dealing with the issue is to limit on-line surveys involving children to research in which the requirements for waiving parental permission can be met.

Informed Consent – Documentation

- Unless waived by the IRB, signed consent for participation in on-line surveys is required.
- This is no different than for mailed or telephone surveys, and the requirements for a waiver can usually be satisfied. Note that waiver of documentation usually requires that the research be minimal risk.
- If waiver cannot be granted, there are methods that could be used to obtain signed consent. E.g., a consent form can be downloaded from the survey site, signed and mailed back to the researcher, who then sends the subject a password to access the survey pages. However, this will inevitably lower the survey response rates.

When Alternatives to On-line Surveys Should be Considered

- When they include highly personal or sensitive topics that may cause adverse emotional or psychological reactions.
- When the research is more than minimal risk and children or other vulnerable populations are involved as subjects.
- When deception which requires debriefing is involved.
- When waiver of documentation cannot be approved.

References:

Cohen, Jeffrey M, "Internet Research: A Brief Guide for Institutional Review Boards," in Bankert and Amdur, Institutional Review Board Management and Function, Second Edition, 2006.

Hicks, Lorna, "Internet Research," a Collaborative Institutional Training Initiative (CITI) module.

Kraut, Robert, et. al., "Psychological Research Online," American Psychologist, February/March, 2004